Changing Minds, Changing Services, Changing Lives for People with RA and JIA
‘Arthritis’ is an umbrella term for many different types of joint disease. Most people assume that having ‘arthritis’ is not very serious and that it is something we all get as we age. RHEUMATOID arthritis (RA) is, on the contrary, a very serious autoimmune inflammatory disease which affects not only joints, but can also affect organs such as the heart, lungs and eyes. It’s not about wear and tear, it occurs when your immune system which normally protects you, is triggered into attacking you from the inside. It can shorten life if not adequately treated and certainly takes away quality of life. The best results and outcomes can be obtained when it is caught and treated AS EARLY AS POSSIBLE.

Juvenile idiopathic arthritis describes a number of types of inflammatory arthritis affecting children under the age of 16. It’s very serious and whilst also autoimmune related, it’s not the same as RA. However, as with RA, the best outcomes can be obtained when it is caught and treated as early as possible, which is challenging when many parents would never assume that a child or young person could get arthritis.

Our goal is to be there for you and everyone diagnosed with RA or JIA right at the start of your journey (and whenever you need us along the way) and to help you to live as normal a life as possible, through understanding your disease and learning how to self-manage effectively so that you are able to achieve the goals you want in life.

Maxine Berry, who has RA herself, achieving her goal of 24 peaks in 24 hours in support of NRAS
Since the turn of the century, we have seen the treatment of rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA) change in a revolutionary way. In fact every year since the launch of NRAS in 2001, we have seen major growth in the research of the pathogenesis of RA/JIA, spawned by the advent of Anti-TNF inhibitors. Innovative new treatments continue to be introduced to meet the unmet need of those adults and children whose disease is, or becomes, unresponsive to currently available therapies. There has justifiably been much emphasis on early diagnosis, treat to target and tight control strategies all of which have been championed by NRAS. We now also need to see more being done to address the complex needs of patients with longer standing disease and co-morbidities as well as those with refractory disease (both in RA and JIA). NRAS has done a lot to support academic and clinical research in the UK and will continue to work in this area. NRAS has also been strategically involved in the development and introduction of national guidelines and quality standards which promote best evidence based treatment and care for all.

In spite of this remarkable progress, there remains significant unmet need and wide variation in the standards of care which people can expect to receive, and our job of supporting people living with this painful and progressive disease remains as important today as it was when we launched NRAS in 2001. Given that RA and JIA are not diseases that can currently be prevented, we need to increase our efforts to champion earlier diagnosis and treatment which improves long term outcomes and is likely to also reduce the onset of co-morbidities and complications further down the line. We have built strong partnerships with health professional organisations such as the British Society for Rheumatology and the Royal College of Nursing, as well as with other charities in the musculoskeletal field and those involved in disability and welfare. We believe that our collaborative working benefits those we represent. As we move forward in the next few years, where the challenge of treating long term conditions (which consume over 70% of the total NHS budget), such as RA, increases with an ageing population and reducing NHS budgets, we believe that our approach to developing supported self-management pathways, as well as working in collaborative partnerships and alliances will enable NRAS to deliver more innovative and integrated services spanning both health and social care.

Ailsa Bosworth MBE
CEO

“I would encourage all health professionals to make use of the outstanding patient support material, services and networks provided by NRAS. No-one understands the subjective burden of rheumatoid better than those who have lived with this condition and experienced both the problems and the benefits of management regimens that really make a difference and the type of support and encouragement that offers best opportunity for optimum outcomes. NRAS excel in all these areas and can ably help you to help your patients.”

Peter C. Taylor MA, PhD, FRCP, FRCPE – Norman Collison Professor of Musculoskeletal Sciences, Kennedy Institute of Rheumatology, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford and Chief Medical Advisor to NRAS
NRAS has been strategically involved in the development and introduction of national guidelines and standards which promote best evidence-based treatment and care for all.
About The National Rheumatoid Arthritis Society:

Changing Minds, Changing Services, Changing Lives for People with RA and JIA

Founded in 2001, we are the only UK charity specifically devoted to supporting adults and their families living with rheumatoid arthritis (RA) and children, young people and their families affected by juvenile idiopathic arthritis (JIA) and the health professionals treating RA and JIA.

We take pride in the fact that everything we stand for and do is patient-led. Our head office team of over 20 members of staff works closely with our NRAS Members and Volunteers, our Board of Trustees and our panel of Medical and Allied Health Professional Advisors as well as our devolved nation Campaigns Networks to design, coordinate, fund and deliver a wide range of high quality products and services for all affected by RA and JIA.

We provide a highly valued magazine to our Members three times a year as well as other Member benefits and everything we do supports a strong belief in the importance of supported self-management strategies, which incorporate care and support planning and shared decision making, underpinning best evidenced based care for all.

Our Core Values

We approach our commitment and responsibilities to all with empathy, professionalism, passion and enthusiasm.

We continually strive to achieve the best results and outcomes that we can for those we represent. These core values underpin the way we work.
At all times, we act:

<table>
<thead>
<tr>
<th>TRANSPARENTLY</th>
<th>We work openly and ethically, with integrity, honesty and independence</th>
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</thead>
<tbody>
<tr>
<td>INNOVATIVELY</td>
<td>We are creative and constantly challenge the status quo, always striving for better and looking for new ways to add value, whilst basing what we say and do on the best evidence as well as input and feedback from our Members’ experiences and those of the wider communities of people affected by RA and JIA</td>
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<td>PASSIONATELY</td>
<td>Our staff are not just enthusiastic and committed, they are passionate about making a positive difference for all those we represent</td>
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<tr>
<td>COLLABORATIVELY</td>
<td>We work with many different organisations, including other charities, alliances and coalitions, as well as the leading health professional organisations in our field</td>
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<td>DECISIVELY</td>
<td>We are results focused and deliver on our projects and campaigns. Our many awards are testament to our achievements</td>
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<tr>
<td>INCLUSIVELY</td>
<td>We act with sensitivity and compassion, respecting the needs and preferences of the individual (regardless of creed, gender, age or ethnicity), while at the same time representing the entire community affected by RA or JIA in the UK, encompassing adults and young people, families, carers and rheumatology healthcare professionals</td>
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"I am sending you this email to say thank you for listening to me and replying to my email. Your action has made me feel that at least there are people who care. On the day I called NRAS I was so down, feeling like I am at the end of the world with no way out. But the way the lady spoke to me and you replying to my email has really lifted my self-esteem and my hope that all will be well, if not perfect."

Helpline Caller
Our Vision
Supporting all with RA or JIA to live life to the full

Our Mission
We will:
- **Support** everyone living with the impact of RA and JIA at the start and at every stage of their journey
- **Inform** – be their first choice for reliable information
- **Empower** all to have a voice and take control of their RA or JIA
Strategic Aim 1

Increase public awareness and understanding of rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA).

Insufficient numbers of people with early RA and parents of children and young people (CYP) with early stages of JIA recognise the symptoms or seek help as early as possible. Raising public awareness of RA and JIA will, over time, increase recognition of the early signs and symptoms so that more people seek help and are diagnosed and treated early leading to improved long-term outcomes and increased possibility of achieving low disease activity or remission.

To achieve this aim, we will:

- improve the quality of interactions as well as grow overall numbers of people we reach. We know we are reaching and interacting with approximately 1 million people in a variety of ways. By 2019 we are targeting to increase this by a third.

- more proactively address the important issue of health literacy when reviewing the content and style of our existing publications and when creating new ones.

- begin to target populations who are known to have poorer outcomes, starting with provision of information on our website about RA for the South Asian community in more accessible formats to suit their needs and culture.

- launch a new ‘HealthUnlocked’ on-line forum so that parents of children with JIA can learn more and support each other in a safe, moderated environment. Initially our target is parents with younger children up to the age of 13. Our goal for membership of this new on-line platform will be 1,000 members by 2019.

- our existing forum for adults with RA has already exceeded 10,000 members and we anticipate growing this by at least another 12.5-15% by 2019 – this site attracts a world-wide audience although our focus is on the UK.

- work with our GP Medical Advisor and other health professional partners to improve implementation of NICE Quality Standards. (Only 17% of patients were referred by their GP to rheumatology within 3 days (NICE Quality Standard 1) and a quarter of patients waited more than 3 months to be referred – BSR/HQIP audit Jan 2016)

- involve more supporters and people with RA and JIA in our policy and public affairs activities to maintain a more widespread appreciation amongst parliamentarians and key decision makers of need for early diagnosis and treatment of RA and JIA.
Strategic Aim 2

We aim to improve the capacity of more people with RA and JIA to self-manage and, at the same time, improve the ability of health and care providers to support them doing so.

There is plenty of evidence (Atlas of Variation, National Audit Office Report on RA services – 2009, ScotPHN Report - 2012, BSR/HQIP early RA Audit - Jan 2016) to quote a few examples, that a worrying number of people do not receive optimal care and treatment. Also, not enough people are self-managing well or getting personalised care and treatment and not enough are helping to shape and improve wider services.

Better health outcomes for people with RA and JIA are a priority and a major determinant of this is access to better guidance and support for self-management, offered to all as part of proper personalised care planning and shared decision making. (Aim 4 also feeds into this).

To achieve this aim, we will:

• continue to develop and promote the efficacy of our supported self-management pathway
• continue to develop and pilot innovative self-management courses and workshops whether delivered one to one, in group face to face format, on-line or by telephone as part of that pathway during 2016-19
• continue to measure and report on impact evaluation of supported self-management interventions
• deliver individual or partnership projects where the health economic value of treatments, care and supported self-management can be demonstrated
• continue to ensure that the need to acquire better self-management skills is promoted to all people with RA/JIA who access our front line services and interact with us via our websites, social media and on-line fora
• collaborate with key health professional partner organisations and support health professionals to promote person centred care as part of routine clinical care. Patient-centred care starts with care and support planning, shared decision making and includes supported self-management
• deliver further Rheum2Talk workshops, funding permitting, to train allied health professionals how to better support patients over sensitive issues
• increase the number of NRAS groups over the period to 60 to enable more people to have access to locally provided peer support and inspiration, leading to a larger number of people learning and acquiring self-management skills and techniques
• contribute as a priority to the development and implementation of national, regional and local service standards and guidelines, which include recommendations around supported self-management, and promote their uptake and implementation.

I just wanted to give you an update on my progress since completing the NRAS RA Self-Management course in January. I was working reduced hours and had failed on multiple attempts to get back to full time work due to exhaustion/fatigue.

Since completing the course I made quick progress after utilising my new ‘toolbox’ and returned to full time hours approximately 2 months later. I was on a graduate scheme which involved presenting to leadership at the end of each 8 month ‘rotation’ in the business. In January I was due to complete a presentation, but felt that I couldn’t cope with the added stress as just completing the reduced hours was exhausting, and I felt I hadn’t achieved in comparison to my peers. In the end I did complete a presentation about RA and everything that I’d learnt on the course, and I said that my aim was to return to full time hours in my final rotation. This was a big step in terms of admitting to myself and others that RA was a part of me, and really helped put this behind me.

Fast forward to today and I’ve just completed my final rotation and my final presentation in line with my peers. It’s been a hugely busy period and in addition I delivered my presentation on Thursday morning. There is no chance I would have managed this 10 months ago, and it was all down to putting into practice the techniques from the course. I feel I’m much more resilient now, which in turn makes me so much happier! I’ve just started a new full time role this week, which in January was something that I wasn’t sure I was ever going to achieve.

I’m absolutely thrilled and would like to say a huge thank you to the team and to NRAS. I recognise that I still have a long way to go, and the journey will have highs and lows, but I know that I’m so much better equipped to deal with them.

Male participant on the NRAS RA Self-Management Programme
Strategic Aim 3

We aim to increase our fundraising capacity in the next 3 years in order to be able to reach, engage and provide support to more people across the UK.

Competition for charity funding is challenging and due to significant changes in statutory services, expectation that the voluntary sector will fill gaps somehow, is high. We intend to increase our income to £1,250,000 by 2019 so that we can begin to meet future demand on our services and provide support to more people who need us.

To achieve this aim, we will:

- attract and encourage active involvement of more people with RA and families affected by JIA in our core activities and work
- increase our membership of NRAS by a further 15% by 2019
- deliver on our new 3-year fundraising strategy, including building our sustainable income streams in line with targets
- build even better relationships with our supporters and donors so that as well as increasing numbers of people supporting us and their contributions they get the maximum enjoyment and satisfaction from supporting the charity
- strengthen our fundraising ability by engaging with more people who wish to support us through greater awareness of RA, JIA and NRAS (Aim 1)
- seek innovative ways to build and broaden our cost-effective commissioned services in line with our ability to resource these, through NRAS Community Services Ltd.

These activities will benefit from those outlined in Aim 1 and also feed into Aim 5.
Strategic Aim 4

Make our services more visible, relevant and accessible to offer the greatest support to all, especially those who need us most.

We are aware that our supporter and beneficiary profile, like a number of health charities, does not reflect fully the increasingly diverse nature of the British population. We are therefore going to take more positive steps to reach out to communities where barriers exist when it comes to accessing health information and guidance which has the capacity to transform their lives.

To achieve this aim, we will:

• build our web and social media activity in appropriate ways to reach younger audiences for whom technology is their preferred way to receive information
• more proactively address the important issue of language and health literacy when reviewing the content and style of our websites, our existing publications and when creating new ones
• add more audio visual material to our website and YouTube channel to meet demand for greater interactive experiences
• begin to target populations who are known to have poorer outcomes, starting with provision of information on our website about RA for the South Asian community
• target the newly diagnosed and families of children newly diagnosed who are likely to be less knowledgeable about their condition. In this respect, by 2019 we aim to reach substantially more of those newly diagnosed with RA or JIA each year
• target men more proactively who are less likely to seek help and support
• ensure that for older people we maintain the provision of hard copy material for those who do not have access to the internet or digital technologies
• build a more diverse Board of Trustees to be more representative of the RA/JIA population we represent.

Awareness raising activities outlined under strategic aim 1 will feed into this aim.
Strategic Aim 5

Influence and shape the policy and service environment to ensure equitable access to the best treatment and care for all with RA and JIA

We know that access to best care and treatment for all is not a reality and there are lots of reports and research to back this up. Our Policy and Public Affairs work is vital in ensuring that those who take decisions about health and social care are informed of the impact that RA and JIA have on lives and wider society, and understand the value that access to the best care and treatment brings to individuals, the NHS, the Exchequer and whole communities. Seeing the right person, with the right skills at the right time, improves outcomes and saves money.

To achieve this aim, we will:

• build on the work of our Campaign Networks in Scotland and Wales and seek to introduce a Network in Northern Ireland in 2018 in order to raise the profile of the charity and the needs of those with RA and JIA in the devolved nations
• seek to introduce Campaign Networks in areas in England where health and social care has been devolved, such as Manchester and London
• proactively seek to engage more members and volunteers in campaigning activities through our website, with local MP contact programmes
• help to shape local services and ensure that we feed into re-design of MSK services wherever this is happening
• proactively identify and promote examples of good practice to encourage improvement in service delivery and outcomes, (one such example is the nurse-led annual holistic review in line with NICE Guideline CG79 and NICE QS33 developed by the Freeman hospital)
• continue to lead on patient input to national standards, guidance and guidelines which recommend best evidence based care in RA and JIA
• continue to work with long term condition coalitions to promote the interests of people with RA/JIA, particularly in relation to social welfare, work related issues and access to treatment
• learn from our delivery of commissioned services to enable NRAS to illustrate and argue for improved access and better services for all.

NRAS Member Fiona McWhirter meets David Torrance MSP in the Scottish Parliament, helping to raise awareness
We will achieve our aims by delivering our products and services through our principal activities.

Our Products and Services

We are committed to providing support, information, services, education and patient advocacy of the highest quality to and on behalf of all those affected by RA and JIA. We also provide a range of services including our valued magazine (three times annually) to our members and also support health professionals in the field of rheumatology so that we can ‘help them to help their patients’.

Living with RA and JIA is not just about having physical and medical needs. These diseases have a huge impact on emotional well-being and quality of life both of the individual and their family as well and often emotional well-being can be more important than the physical. We therefore strive to help people by supporting all their needs in a holistic way whether physical, medical, emotional, mental, social, economic and/or employment related needs as well as those relating to access to benefits and the built environment, housing and transport.

Our comprehensive range of services includes the following:

- Free professional helpline
- Comprehensive websites for RA and JIA
- Wide range of publications and other sources of information, all Information Standard accredited
- Range of services and information specifically relating to JIA
- Membership of NRAS, with major benefits
- Health professional membership programme
- National volunteer network
- Community based NRAS groups across the UK
- HealthUnlocked NRAS on-line community
- Telephone Peer support service
- Self-management education – a range of programmes and interventions to support people to improve their ability to self-manage and cope with their disease day to day
- Education for people living with RA and JIA, and for the Health Professionals working in rheumatology
- Campaigns Networks for the devolved nations and introducing such Networks to areas in England where health and social care are devolved
- National policy and public affairs programme
- Media and communications programme to raise public awareness of RA and the needs of people affected by RA and JIA
- Fundraising events (national and local) to fund and support our work
- Range of directly commissionable services and consultancy from NRAS and through the Musculoskeletal Support Alliance (an Alliance with the British Society for Rheumatology and Arthritis Care)
- Support for research studies, both clinical and academic.
Our Principal Activities include:

- supporting, informing, educating, and advocating on behalf of people with RA and children and young people with JIA, their carers and families as well as health professionals in adult and paediatric rheumatology
- improving patient self-management skills and helping people to learn to successfully navigate the NHS system and participate fully in decisions about their care and treatment or their child’s care and treatment
- raising public awareness of RA and JIA
- contributing to the creation and development of national guidelines and standards of care in RA and JIA
- providing information and expertise to external organisations such as NICE, The Scottish Medicines Consortium, and NHS England
- providing a range of supported patient self-management programmes, interventions and services which can be directly commissioned to improve patient outcomes
- providing consultancy services to Clinical Commissioning Groups and Clinical Support Units in our own right and as part of the Musculoskeletal Support Alliance in partnership with The British Society for Rheumatology and Arthritis Care
- campaigning at national, regional and local government level to influence policy and public affairs and improve access to best services for all
- influencing stakeholders, such as commissioners and key opinion leaders on RA and JIA related issues
- working collaboratively with the musculoskeletal community and relevant long term condition and disability organisations to improve health and social care outcomes for RA and JIA as well as wider MSK conditions
- conducting our own social research in respect of the impact of living with RA and JIA
- supporting clinical, academic and health and social research in the UK. Contributing patient research partners to national and international research programmes
- contributing to the development of patient reported outcome and experience measures
- continuing to develop our service for children, families and young people affected by JIA.
Dear Victoria,

I wanted to email to thank staff at NRAS for organising a phone call from Sue – it was so good to talk, laugh and share our experiences in terms of the condition both negative and positive. It felt incredibly cathartic to hear similar issues/concerns and not feel bad, alone or a failure. I wish I’d done this earlier instead of stressing! Prior to the call I was struggling, particularly with regard to my career, however, by listening to Sue I feel open to possibilities should this be the outcome – a big hug and thanks to you all.
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Registered Charity Numbers 1134859, SC039721

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